

The data management role offered by the ENCR secretariat and the JRC

Introduction

The secretariat of the European Network of Cancer Registries (ENCR) is hosted at the European Commission's Joint Research Centre (JRC) in Ispra, Italy. The secretariat supports the ENCR Steering Committee at an operational level.

The ENCR Steering Committee, acting on behalf of the ENCR membership, is committed to ensuring: a single point of data submission; a common data standard; and a standard data-submission protocol and a common quality-control procedure. This will avoid development of conflicting data repositories of the same data, the time consuming query and data-cleaning process of submitting data to several entities, each requiring different data formats, as well as limiting the number of resulting databases holding European cancer registry.

In order to realize this goal, the ENCR secretariat, via the IT infrastructure at the JRC, has developed the ENCR-JRC data portal.

The portal allows cancer registries to submit their data following a single process and thereafter elect the JRC to act as their data-manager. The JRC will perform this service strictly on the conditions specified by each registry at the time of data submission. In this role, the ENCR secretariat will receive the data and perform the necessary data quality control procedures, providing feedback to the registries. The secretariat will support the ENCR in evaluating the correct epidemiological design and statistical methodology of proposed studies for the production of statistics; and act on behalf of the registry as the first liaison point concerning data delivery with studies' principal investigators or individual researchers.

Different data studies

The ENCR-JRC portal allows individual cancer registries to select the studies in which they wish to participate and with which particular data-usage restrictions. It is the duty of the cancer registry to obtain permissions as needed by national data-protection legislation to any transfer of data from the ENCR data repository to third parties.

The ENCR-secretariat, on the basis of the selections made, will act as the interface between the cancer registries and the associated study coordinators and will handle the complete data-transfer process from start to finish. In order to secure that ENCR holds the controlled and accepted core data, the ENCR secretariat must be copied on all communications between the study coordinator and the registries. Moreover the complete data set (rather than the individual records corrected) must be resubmitted through the ENCR-JRC portal.¹

Access to the ENCR-JRC portal is protected by the European Commission's authentication service (ECAS). Within a few hours of a cancer registry's data submission, the data are removed from the portal and temporarily stored behind the JRC's firewall. Prior to temporarily storing the data, any further pseudonymisation of identifiers is performed (which may be required by the submitting registry in order to comply with the country's laws on personal data). In this case, the table linking the new pseudonymised identifier to the old pseudonymised identifier is stored in one of the JRC's secured stand-alone servers.

Cancer registry data submitted to the JRC are treated in full confidentiality by the JRC. The ENCR secretariat will only transfer a cancer registry's data to a third party when explicitly requested by the registry and according to the limitations specified by the registry. JRC cannot however be held responsible for any breaches of the data-usage agreements caused thereafter by the third party, and any legal infringements occurring as a result will be a matter between the cancer registry and the third party concerned.

1. A standard operating procedure will be followed by which, following data submission, the data go through a process of cleaning. JRC will keep in secure storage the data submitted via the portal until the final cleaned version of the data has been agreed. JRC will then delete from its server all the previously submitted data sets and confirm via the portal the final agreed version of the data set. Depending on the instructions provided by the registry, JRC will then confirm with the third party the final version of the data and afterwards either delete the final remaining data set from its servers or upload it into the Commission's secured and non-public European cancer registry database.

Transmission of data to a third party

Data transferred to third parties on the request of a cancer registry will also be handled via the ENCR-JRC portal. The third party will be informed that data are available for download and the data set will be removed from the portal within a few hours of its posting. The data will only be accessible via an authorized login from the third party.

ENCR/JRC as data users

For the purposes both of the ENCR Steering Committee and of the European Commission, the JRC is establishing a database of European cancer registry data for the following purposes:

- Establishment of a service for single record-level data access among cancer registries where permissions have been granted;
- European monitoring and inter-comparison of cancer incidence and mortality rates (including time trends);
- Further development towards a comprehensive European Cancer Information System;
- Public access to anonymised and aggregated European cancer registry data.

In this respect, ENCR and JRC are no different from other third parties mentioned above and both entities bind themselves to follow exactly the same principles and to fully respect any limitations and data restrictions specified by the registries. Moreover, JRC in liaison with the ENCR Steering Committee will actively invite the involvement of single registries in all aspects of this work (scientific as well as development), where they have an interest to be involved.